

My name is Amanda Richards. I am from Derby and I would like to provide testimony in support of SB 918. I attended the Press Conference in February in which we presented the “Our Families Can’t Wait” petition opposing DDS budget cuts to the Appropriations Committee. After hearing heart felt testimony from parents and care givers that day, I want to express my dissatisfaction regarding DDS budget cuts. There is a desperate need for a fully funded system. As a mother of two severely autistic twin daughters, I understand how helpless these parents feel. These parents have selflessly dedicated their lives to caring for their disabled children. They have endured the trials and hardships that come along with each and every day of their child’s life. As if it isn’t hard enough to see your child unable to do or experience things typical children are capable of, parents, on top of this, are expected to care for their child that has such a high level of need, all on their own. It isn’t right and the time has come for this state to give these families the support that has been long overdue.

I would like to provide you with a glimpse into my life, which will explain why I am such a strong supporter of SB918. As I mentioned, I am the mother of two severely autistic twin girls. I am currently seeking residential placement for my twin daughters. My daughters, Alaina and Chloe, are currently clients of the DCF Voluntary Service Program because they are not yet age 8, the age which DDS will begin funding children like mine. Both Alaina and Chloe have been diagnosed with autism and mood disorder. Their autism is severe and they are extremely low-functioning with self- injurious behaviors. They are non-verbal and not toilet-trained, despite intense efforts at home and at school over the past three years. I am a single mother and recently had to leave my teaching position at the end of this past school year to continue to be able to care for my daughters. After three leaves of absences over the past two years, my psychiatrist strongly recommended that I file for disability because of the depression, anxiety, and exhaustion, that have been a direct result of dealing with my situation. I have been actively advocating for additional supports for Alaina and Chloe in my home. I have letters from various doctors including their pediatrician and psychiatrist, stating that Alaina and Chloe both need 1:1 supervision at all times. Through VSP I have received ABA services from ACES 6 days a week and respite services on Sundays. This sounds great in theory, however, ACES services are often cancelled due to weather and staffing issues. In addition, I have had several issues over the past year with the quality of staff and the reliability of staff from the agencies providing respite including Inclusion First and now Adelbrook. I am constantly given lame excuses at the last minute of why staff will not be reporting for their shift. I desperately rely on the support that these agencies are supposed to provide, yet I am often times left to struggle to care for my daughters on my own. This is an excruciatingly difficult task when both of your children engage in self injury and other dangerous behaviors such constantly breaking household items, smearing and eating their own feces, and eating inedible items including glass, cat food, cat litter, and anything else they can get their hands on. Both of my children have also bolted from my home several times and their lives have been endangered because of this.

My daughter Chloe has been engaging in severe self-injurious behavior for the past 4 months. Prior to this, my other daughter Alaina had experienced intense self-injurious behavior for a period of 6 months earlier in 2014. I have brought her several times to the ER at Yale the Children's Medical Center in Hartford. No one, including her pediatrician, neurologist, psychiatrist, etc., has been able to help Chloe. She has been on a waiting list for the past month to be admitted to an in-patient intensive neurobehavioral program at Bradley Hospital in Rhode Island. In the meantime, I watch helplessly everyday as Chloe rips her hair out, claws the skin off her face, smashes her head up against walls and windows, and cries incessantly the majority of the day. Even though I do my best to console Chloe and restrain her from hurting herself, it's an on-going battle. I have been dealing with these extremely severe behaviors for almost the entire past year between the both of my daughters.

My daughters are 6 years old and have been going to The Foundation School in Orange for over a year now. I have seen little to no progress with their pre-academic programs. They also lack any independent daily living skills. At their recent triennial review, it was reported by the school psychologist that their current level of functioning is approximately that of a one year old, and that is being generous in my opinion. I cannot provide both of them the level of care that they require. I have been struggling for the past 6 years to keep them safe and meet their basic needs. However, this comes at a great cost. My health is in jeopardy and my financial situation is getting worse and worse, as I do not have the income to keep up with my mortgage and monthly bills. I am on call 24 hours a day, from the moment they get up at 4 or 5 in the morning until the time they go to sleep and during the night when they frequently wake up crying inconsolably or having self-injurious tantrums. I am up and down constantly every night and this kind of broken sleep takes a toll on your body. This is no quality of life for me and my children. I have mentioned to my case worker several times that I would like to see them placed in a residential facility, but he has informed me that nothing exists in CT. I truly believe that they are prime candidates for a 24 hour care facility. However, since the philosophy of DCF in CT is to keep children in their home with their family, I feel my pleas for residential placement have been discouraged and discounted. I'm sorry, but I do not agree that keeping children as severe as mine in their own home is in the best interest of me and my family.

I can certainly relate to the frustration and disappointment that these parents are going through. I myself will most likely be in their shoes one day down the road, if I make it that far. These families desperately need support and will not receive it if the DDS budget is cut. Please take these families, who have selflessly carried the burden of caring for the most vulnerable members of our society, into consideration when making your decision in allocating funds.

Sincerely,

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